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“Is there a medicine for these tensions?” Barriers to treatment-seeking for depressive symptoms in rural India: A qualitative study

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ABSTRACT

Rationale and objective Fewer than 15% of adults who meet criteria for a depression diagnosis in India seek treatment for these symptoms. It is unclear whether this reflects limited supply of mental health services or lack of demand for medical intervention for these experiences. This paper aims to identify and describe self-reported barriers that contribute to this “treatment gap” in a rural district in central India, where depression treatment had recently become available in primary care facilities.

Method: In this qualitative study we conducted in-depth interviews with 35 adults who screened positive for depression and who had not sought treatment for their condition, and 15 of their relatives. We analysed the data using the framework approach.

Results: A key barrier to seeking health care for psychological symptoms was lack of perceived need for treatment for these symptoms. Low perceived need for health interventions arose because participants frequently attributed depression-like symptoms to their socio-economic circumstances, or to the stress of physical illness, which conflicted with the biomedical approach associated with health services. Despite widespread recognition of the links between psychological symptoms, social circumstances and physical health, it was believed that health care providers are equipped to treat only somatic symptoms, which were commonly reported.

Conclusions: Low demand for depression treatment reflected discrepancies between the community's perceived needs and a narrow biomedical model of mental health. Meeting their needs may require a radical change in approach that acknowledges the social determinants of distress, and the interactions between mental and physical health. The capabilities approach may provide a framework for more holistically conceptualising people's needs.

1. Introduction

The notion that the central challenge of public mental health is to ensure that mental health expertise reaches more people has been dubbed the “reach paradigm” (Knibbe et al., 2016). The ubiquity of “treatment gap” statistics as a framework for assessing unmet needs, referring to the proportion of people who meet diagnostic criteria for a disorder who do not receive treatment (Kohn et al., 2004), demonstrates the pervasiveness of this paradigm in global mental health. According to the World Mental Health Surveys, 75% of adults in low-

and middle-income countries who meet diagnostic criteria for depression use no services for these symptoms (Kessler et al., 2010). Similar figures appear in almost every global mental health research article, policy document and advocacy initiative. This apparent enormous level of unmet need for care has led to calls to “scale up” mental health services globally, as a central priority of the field of global mental health (Chisholm et al., 2007), and is cited as the rationale behind initiatives to expand access to mental health services around the world such as the World Health Organization's Mental Health Gap Action Programme (World Health Organization, 2008), which has now been

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implemented in over 90 countries (Keynejad et al., 2018).

The conceptual underpinnings of this approach can be contested on two inter-related fronts: first, whether the diagnostic categories used appropriately capture population mental health needs across settings, and second, whether seeking individual treatment for mental health problems adequately conceptualises appropriate responses to these needs. Kleinman (1977) argued that the application of Western psychiatric categories to non-Western societies represents a “category fallacy”, by assuming that classification systems that originate in Europe and North America are independent of cultural bias, while local variation in phenomenology and explanatory models represent “layers of cultural camouflage” to be stripped away. He illustrates divergence in experiences of emotional distress between settings with the example of somatization in China, suggesting that applying standardised diagnostic categories across cultures may yield estimates of mental health needs that lack relevance to the local population. More recent research echoes this concern that universal criteria fail to reflect locally meaningful constructs, given variation in experiences and idioms of distress between settings (Haroz et al., 2017; Kirmayer et al., 2017).

Another line of critique relates to the decontextualisation of suffering. Mills (2015) argues that translating situated accounts of suffering into context-free psychiatric diagnoses involves abstracting symptoms from their personal and social context, and framing problems as brain-based disorders, rather than a sign of disruption in a person's “lifeworld”; that is, those experiences, activities, and social networks that make human life meaningful (Lewis-Fernández and Kirmayer, 2019). Framing mental health problems in individual terms thus obscures the role of wider determinants, and encourages the provision of medical interventions rather than public health approaches (Jacob, 2013; Jacob and Patel, 2014).

Relatedly, the reach paradigm implies that appropriate support consists of individual treatment, thus excluding community-level responses, or action on the causes of distress. Collective action such as unionisation to protect employee rights, campaigns to change policies, or protest movements, do not fit within this model (Knifton, 2015). Summerfield (2013) describes how a gift of a cow provided an effective “antidepressant and painkiller” for a farmer in Cambodia whose distress arose from income insecurity; another intervention that doesn't fit the paradigm.

It is unclear, therefore, whether the treatment gap should be interpreted as indicating vast unmet need for mental health services, as it is often presented in global mental health initiatives (e.g., Lund et al., 2012), or a sign of low demand for biomedical solutions to what are perceived as social and economic problems (Burgess and Campbell, 2014). In India, the treatment gap for depression is estimated at over 85% (Gururaj et al., 2016), which is usually attributed to lack of supply of mental health services, but little research has empirically addressed barriers to service use. Previous Indian studies of idioms of distress – i.e., how people within a cultural group experience, understand and communicate their suffering (Nichter, 2010), which may influence help-seeking behaviour – have largely focussed on facility-based populations or specific sub-groups such as perinatal women (Andrew et al., 2012; Patel and Prince, 2001; Pereira et al., 2007; Rodrigues et al., 2003) which may not generalise to the general population in the community.

Jain and Orr (2016) argue for more constructive dialogue between those engaged in implementing global mental health interventions and those who critique the concepts and approaches employed, but such dialogue can be hindered by differences in theoretical frameworks and methodological approaches. The current study is an attempt to directly nest a qualitative study of barriers to treatment-seeking for depression within a large-scale global mental health initiative – the Programme for Improving Mental Health Care (PRIME) (Lund et al., 2012) – using the same measures and definitions as employed by this programme, in order to empirically investigate the reasons for the large treatment gap reported (Rathod et al., 2016). No reduction of the depression

treatment gap was observed following the establishment of integrated mental health services, described below (Shidhaye et al., 2019). By aligning the parameters of this study with the larger programme, we hope to advance a shared understanding of the nature of the gap.

The current study focusses on those who screen positive for depression; by far the most prevalent of the conditions targeted by PRIME. The aim of this study, therefore, is to investigate the nature of the treatment gap by identifying and describing barriers to seeking health care for symptoms of depression (as defined by PRIME), among a community-based sample of screen-positive adults and their relatives, in a rural district of Madhya Pradesh where mental health services had recently been established.

2. Method

2.1. Setting

This study focusses on the general adult population of Sehore sub-district, where a Mental Health Care Plan has recently been implemented in partnership with the state and district government, as part of PRIME. The study area (Shidhaye et al., 2015b) and available mental health services (Shidhaye et al., 2016) have been described in detail elsewhere.

Briefly, Sehore sub-district is a largely rural area in Sehore district, Madhya Pradesh, where infant and maternal mortality rates are high (ACCESS Health International, 2016), literacy levels are 81%/58% (male/female), and 31.7% live below the poverty line (Reserve Bank of India Government of India, 2013). The majority of residents work in agriculture (Indian Census, 2011). 88% have completed primary education or less (Rathod et al., 2015).

PRIME aimed to reduce the treatment gap for depression, alcohol abuse, and psychosis, by implementing packages of care through primary healthcare facilities in five countries, including India. Treatment for these conditions were integrated into primary care services, starting in August 2014, with treatment delivered by non-specialist health workers (case managers). Screening was conducted by case managers in health care facilities, although due to human resource limitations this did not occur in all clinical encounters. Case managers also visited villages to conduct screening, but could only screen a small proportion of adults (Shidhaye et al., 2019).

As part of the PRIME evaluation, adults receiving treatment were interviewed to understand their experiences (forthcoming). However, the perspectives of the nearly 90% of those who screened positive for depression but did not seek treatment (Shidhaye et al., 2019) – which are crucial to understanding why so few seek care – have not been explored.

2.2. Sample

This qualitative study was nested in the follow-up round of a population-based community survey of adults in Sehore, conducted in October–December 2016 (26 months after initial implementation of the Mental Health Care Plan). The survey aimed to measure the change in proportion of people who screened positive for depression or alcohol use disorders who sought treatment for these symptoms (De Silva et al., 2016). Eligibility criteria for this qualitative sub-study were: being aged 18 and above, residency in the implementation area, fluency in Hindi, screening positive for depression (defined as scoring ≥ 10 on the PHQ-9 (Moriarty et al., 2015)), having given permission to be re-contacted after the community survey, not having sought depression treatment in the 12 months prior to the community survey, and willingness and capacity to provide informed consent.

The PHQ-9 was originally developed in the USA (Kroenke et al., 2001), but has been used widely in cross-cultural research, including in India (Dutta et al., 2013; Thour et al., 2015; Umadevi, 2019). It has been validated against structured diagnostic interviews in India; good

psychometric properties were reported for adolescents in Kolkata (Ganguly et al., 2013), but it had poor positive predictive value for adults in Goa (Patel et al., 2008). Despite its limitations, and the more general critique of using standardised measures across settings (see above), we used the PHQ-9 to reflect the way in which the treatment gap for depression was measured in PRIME.

In this sub-study, we used purposive sampling to ensure adequate sample variability with regard to our primary sampling criteria; gender, symptom severity as per the PHQ-9, and age. This involved intentional over-representation of individuals reporting higher levels of symptoms, since previous research suggests that barriers to treatment-seeking vary by symptom severity (Andrade et al., 2014). We also asked the screen-positive individual to nominate a close relative to be interviewed, as decisions are often taken at the level of the family within this cultural context (Nunley, 1998). We chose to interview the pair separately to hear both perspectives, rather than only the head of the household's, and to allow for comparisons between the screen-positive individual and their family member. Relatives were informed that we wished to interview them about their relative's health and use of health services, but the terms "depression" and "mental illness" were not used.

We aimed to recruit at least twenty adults who screened positive for depression and twenty relatives, but continued recruiting participants until data saturation was reached. A research assistant contacted selected participants by telephone or at home, explained the purpose of the interview, read out an information sheet, and answered any questions. Participants were excluded if there was any doubt about their ability to understand this information, for example due to intellectual disabilities. Informed consent was indicated with either a signature or a thumbprint. Consent procedures for relatives and screen-positive individuals were identical. All participants who were not receiving treatment were referred to services.

2.3. Data collection

Data were collected via individual semi-structured interviews, conducted in Hindi by a trained researcher (the second author) between February and April 2017. Interviews lasted 30 min on average. The interviewer was female, educated to Master's level in India, and had prior experience conducting qualitative interviews. It would have been evident from her name, accent, and style of dress that the researcher was well-educated, middle-class, and unmarried. The first author – a Caucasian British female, educated to post-graduate level in the UK – was also present for all interviews. Participants had not previously met the interviewer, but efforts were made to establish rapport through general conversation, answering participants' questions, and the sharing of chai, before commencing the interview. Participants understood that the research was intended to inform health service planning, although the term "depression" was not used, and it was emphasised that the researchers were independent of the Ministry of Health. Participants were interviewed individually, in or near their homes or places of work. Efforts were made to ensure privacy, to the extent possible given local cultural norms.

Interviews were audio-recorded with participants' permission and subsequently transcribed and translated into English. The accuracy of translation and transcription was checked by the second author, who is fluent in both Hindi and English. Identifying details were removed from the transcripts prior to analysis. Field notes were taken on the context of interviews and body language of participants, and were reviewed during the process of analysis.

2.4. Topic guide

We developed a topic guide based on our research questions and informed by both previous literature and preliminary findings from analysis of the community survey data. The guide covered explanatory models of the symptoms reported in the Patient Health Questionnaire-9

(PHQ-9), perceived need for care, perceptions of health services, barriers to service use, and logistics of using health services. The guide was translated into Hindi then independently back-translated to check for equivalence of meaning, and adjusted in response to piloting to ensure that the questions were comprehensible to participants. Small adjustments were made throughout the data collection process as new themes emerged, to ensure that these were fully explored. The topic guide for relatives followed the same format as for screen-positive individuals. The full topic guides can be found in the supplementary materials.

Following the methods used in PRIME (De Silva et al., 2016), the term "depression" was not used in the topic guide. Instead, we referred to the symptoms listed in the PHQ-9, which includes emotional and psychological symptoms, such as low mood and anhedonia; insomnia; appetite problems; lack of energy and concentration; and restlessness or slow movements. In this report, for brevity we use the term "depression symptoms" to refer to this cluster of symptoms.

2.5. Analysis

We first present the demographic and depression-related characteristics of the participants, and the relationship to their participating relative, using counts and percentages. To analyse the data, we followed Gale et al.'s recommended steps for applying the framework method (Gale et al., 2013). These steps involve familiarisation with the interview data, open coding, the development of an analytical framework through iteratively grouping codes and refining categories, indexing all transcripts using the coding framework, and then charting the data into a framework matrix. The first and second author both coded the transcripts and developed the codebook through a collaborative process. Coding proceeded inductively, to allow new insights about this population. Codes were subsequently grouped into the three themes discussed in previous literature; perceived need for healthcare, attitudinal barriers, and structural barriers, following the categories used in the World Mental Health Surveys (Andrade et al., 2014), which broadly mirror the categories from the Andersen socio-behavioural model of health service utilisation (need, predisposing and enabling factors) (Andersen, 1995). This facilitates comparison of these results with existing literature. We used NVivo 11 qualitative data analysis software to assist with coding and generating the matrix. Data from screen-positive individuals and relatives were compared within dyads. The coding framework can be found in the supplementary material.

Due to the challenging logistics of contacting participants and low literacy rates, it was unfortunately not possible to return transcripts to participants for comments or to review the findings. Nonetheless, the second author checked the findings against the original Hindi recordings and transcripts.

2.6. Ethics

Institutional review boards at the World Health Organization (Geneva, Switzerland), the University of Cape Town (South Africa), and Sangath (Goa, India) provided ethical approval for the community survey. Ethical approval for this qualitative study was granted by the Sangath (Panjim, Goa, India) Institutional Review Board (TR(NSA)_2016.27) and the London School of Hygiene & Tropical Medicine (London, United Kingdom) Observational Ethics Committee (11912). On concluding the interviews, all participants who were still experiencing symptoms and who were not receiving treatment were referred to the nearest public health facility where depression services were available.

3. Results

3.1. Sample characteristics

Fig. 1 summarises the recruitment process. In total, we selected 46

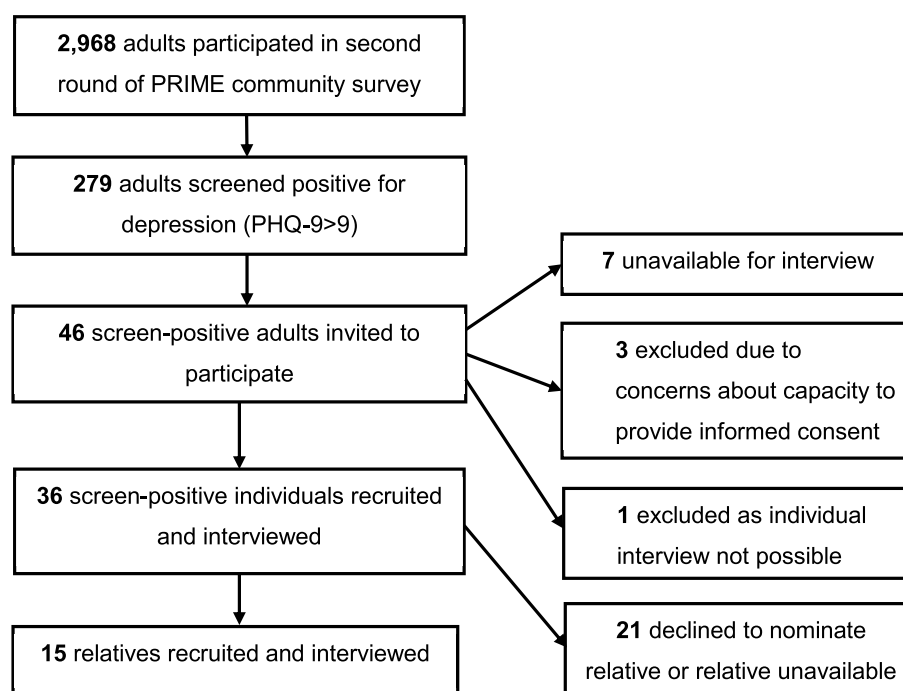


Fig. 1. Recruitment flowchart.

individuals from the community survey to participate in this qualitative study. Potential participants were selected for each day of data collection and sample characteristics were monitored on an ongoing basis to ensure that the final sample was diverse in terms of gender, age and symptom severity. Of the 46 selected, we excluded ten (seven due to unavailability for interview, three because of concerns about capacity). All 36 individuals who were successfully contacted provided informed consent. One interview was excluded from analysis because the family were present and repeatedly answered questions on behalf of the screen-positive individual. We were unable to recruit a family member for 20 participants due to unavailability or participants declining to nominate a relative for interview. We met the target sample size of 20 screen-positive individuals, though continued to recruit until we had 35 participants and 15 relatives, at which point we judged that data saturation had been reached.

Table 1 shows the characteristics of the individuals who screened positive for depression ($n = 35$) and the relationships of the relatives interviewed to these individuals ($n = 15$). Note that these characteristics are based on interviews from the PRIME community survey, whereas qualitative interviews took place up to six months later.

3.2. Responses to the data collection process

Following local custom towards guests, participants were extremely welcoming of the research team. Potential interviewees were inevitably curious about the team's origins and objectives, and we would answer questions before the interview. Power imbalances were evident; for example, when asked direct questions participants often described themselves as "villagers with little education" whereas we were "educated people from the city", so they assumed we knew more than they did. Some probing and reframing of the questions was necessary to encourage interviewees to explain their perspectives. Older men – who may be treated as authority figures locally – were generally more willing to accept that they had knowledge that we lacked.

The role of the first author during interviews was as a silent observer. After the initial curiosity subsided, most interviewees either ignored her presence or directed their comments to both researchers. The second author, who had recently conducted qualitative interviews

Table 1
Demographic and depression screening characteristics of qualitative study participants in Sehore District, India, 2017.

Variable	Mean (SD)	N (%)
Gender		
Female		21 (60)
Male		14 (40)
Age, years	42.3 (14.5)	
18-29		7 (20)
30-49		14 (40)
50-70		14 (40)
Education level completed		
Less than primary		24 (69)
Primary or more		11 (31)
Religion		
Hindu		32 (91)
Muslim		3 (9)
PHQ-9 score	12.8 (2.3)	
Moderately severe (15–19)		9 (26)
Moderate (10–14)		26 (74)
Gender of relative		
Male		10 (67)
Female		5 (33)
Relation to relative		
Spouse		11 (73)
Sibling		1 (7)
Aunt/uncle		1 (7)
Son/daughter		1 (7)
Son/daughter-in-law		1 (7)

in the same area without an observer present, considered there to be little difference between these two studies in the extent to which interviewees were willing to talk openly. Translation did not occur simultaneously. Therefore, we conducted a debriefing after each interview, in order to discuss the overall narrative and key themes.

Maintaining privacy was challenging, but this challenge was usually surmountable. Families often appeared bemused by our request to speak to people individually, but humoured us with the caveat that they remained nearby. The most acceptable format involved interviewing participants outside, where we were visible but out of earshot of family members. Our interest in interviewing relatives allowed us to reassure

them that their perspective would also be heard. Interviews were regularly interrupted by curious neighbours, at which point we would pause, explain what was happening, request privacy, and wait for them to leave, before resuming the interview. In a minority of interviews, it was not possible to interview participants out of hearing range of their family, which may have led them to withhold information.

3.3. Principal themes reported

Participants often mentioned barriers to health service utilisation that were not specific to depression, such as lack of time. However, exploration of participants' perceived health status, their explanatory models of depression symptoms, and their perceptions of the role of health services, revealed that most participants did not consider themselves to need health care for depression symptoms specifically, suggesting that they would have been unlikely to seek care for these symptoms regardless of general barriers to health care use.

The results section will therefore primarily explore the issue of low perceived need for depression treatment, which emerged as the key barrier to seeking care for depression symptoms specifically. In what follows, we distinguish treatment-seeking for depression symptoms, understood as those symptoms listed in the PHQ-9, from the use of health care for other reasons. This approach reflects the measurement of contact coverage and the treatment gap, which excludes treatment-seeking for somatic problems (De Silva et al., 2016; Kessler et al., 2010). A summary of findings on general barriers, including factors that have been hypothesised to inhibit treatment-seeking but which were not supported by the current evidence, are presented in the supplementary material.

Findings from screen-positive individuals and their relatives are presented together, as there was substantial overlap in their reports, but we also compared findings within dyads and present the differences identified below.

Perceived need for change in social and economic circumstances. Participants frequently pointed to social and economic factors as the source of their depression symptoms. As such, none of the participants conceptualised their psychological state in terms of illness, and medical treatment was not regarded as a viable solution. They spoke of their symptoms in terms of worries or "tension" (stress), which were seen as a normal response to adversity, particularly poverty. Over half of the total sample described issues relating to financial hardship and work-related issues as their primary problem. For example:

"Money is the issue. We have no money in our home. If I had money then all of my tension would be ended." – 43-year-old male, moderate symptoms

"Tension of being in shabby and poor conditions. Tension of not being able to fulfil the household expenditures and children's needs. Tension of not having enough earnings ... Tension of my non-working husband" – 39-year-old female, moderate symptoms

Problems related to marriage and the family were also cited by more than half of the interviewees, which medical providers were also seen as unable to address. For instance:

"My son and I fight and argue daily ... What should I say to the doctor ... Can he come and stop my son from fighting with me? ... I am asking you, is there a medicine for these tensions?" – 70-year-old male, moderate symptoms

"It's not any kind of disease ... I have deep sorrow ... I gave birth to five girls then finally we got one son but he died ..." – 35-year-old female, moderate symptoms

The hardships that participants experienced, and to which they attributed their emotional state, were considerable. Nine participants described the premature deaths of close family members (excluding parental deaths when participants were adults), either due to illness or accidents. Participants aged over sixty undertook manual labour in searing heat. Some female participants described alcoholic, abusive, or economically inactive husbands, who left them to bear the family's expenses alone on daily labourers' wages. Families with their own land described borrowing money to invest in agriculture, only to lose everything if the rains arrive too early or too late. There were frequent references to the stress of getting their children married (particularly daughters) and educated (particularly sons), which were seen as vitally important but were bound up with financial pressures.

The context for all of these issues was the unrelenting stress of living in poverty. When asked what kind of help participants needed to alleviate their distress, many spoke not of health services but of the need for financial support, change in their social situation, and routes out of poverty for their families. For example:

"No doctor can treat worry and your mind ... The worry and stress which you have 24/7 only God or money can cure it ... [The doctor] can't provide bread to your home. When your hunger will be ended then your mind will become fine ..." – 63-year-old male, moderate symptoms

"The most important and huge tension for me is debt ... If it [debt] will get solved then my tension will get ended." – 36-year-old female, moderate symptoms

"Once the kids get educated they will support us. Then there won't be any issue of disputes and sorrow." – Relative of 43-year-old male, moderate symptoms

"For me the most difficult thing is my husband ... If my husband was good then there would not be any sorrow in the family." – 39-year-old female, moderate symptoms

While both men and women referred frequently to financial pressures, female participants were more likely to refer to marital problems as a cause of their distress (although some male participants also mentioned these). Several participants mentioned the existence of government welfare schemes to alleviate financial problems, such as Below Poverty Line (BPL) cards, widows' pensions, disability pensions, financial support for the elderly, insurance schemes for crop failures, development programmes to improve housing conditions, and programmes to support members of disadvantaged castes. However, many expressed frustration at being unable to access these programmes, either due to strict eligibility criteria, or to the "sarpanch" (village leader) failing to pass these benefits on to those in need. For example:

"We are Thakur by caste [general caste] so that's why we don't get any benefits" – 43-year-old male, moderate symptoms

"The government introduced so many schemes for poor people but ... the sarpanch is not providing any benefit to us ... He favours rich people and known people ... Look at me, how old I am. I am very elder but they say you don't fulfil age criteria." – 65-year-old female,

Box 1

Somatic complaints reported by adults with probable depression.

Limb pains, headaches, backaches, swelling, chest pain, kidney pain, vision problems, fevers, vomiting, diarrhoea, high blood pressure, fainting, urinary tract infections, vaginal discharge, abscesses, haemorrhoids, digestive problems, bowel problems, respiratory problems, nose bleeds, arthritis, allergic rashes, injuries, heart disease, kidney failure, gum pain, dental problems, strokes.

moderate symptoms

Perceived need for effective physical health care. At the same time, almost all participants described somatic complaints (see [Box 1](#) for a list of somatic problems mentioned) for which health care was seen as appropriate, and most participants had sought treatment for these symptoms. Many participants described pain and other somatic issues as the problem that bothered them the most, particularly when these affected their ability to work. Older participants were somewhat more likely to describe their primary problem as a physical health issue, although it was also common among younger interviewees. Unlike depression symptoms, somatic symptoms were considered to be medical problems that fell within the remit of health care, irrespective of their cause.

Participants had varying models of how their depression symptoms related to their somatic symptoms. A substantial minority of the sample attributed their psychological problems directly to the stress of being physically unwell. For example:

“Due to illness my mood was not good ... I had tension for my illness only” – 37-year-old female, moderate symptoms

“When my body is not healthy then it makes everything unbalanced. If there is any difficulty in your body it is quite obvious it will reach to the mind” – 43-year-old male, moderate symptoms

Those who considered their psychological symptoms to be caused by physical illness perceived a need for treatment for their underlying physical ailments only, and believed that their depression symptoms would disappear if these were effectively treated. For instance:

“If my pain will be cured so maybe this tension will be cured.” – 54-year-old male, moderate symptoms

“If [my] hands and legs get cured then [my] tension will end” – 36-year-old female, moderate symptoms

An important source of stress for many participants was their dissatisfaction with the health care they received for their somatic complaints. Several participants reported having sought treatment multiple times, sometimes at great cost, without lasting improvements in their condition. They also complained about the provision of treatment without physical check-ups to accurately diagnose and treat any physiological disorder, or to rule organic disease out. For instance:

“I am taking treatment probably from ten years, I am still not recovered ... When I don't get relief here [in the village] ... I go to there and there have to pay 1000 rupees [approximately \$14 USD], and I get relief for two-six days then again it is the same” – 63-year-old male, moderate symptoms

“They don't do proper tests and investigations in government hospitals, they only write the prescription based on your verbal complaints” – 33-year-old male, moderate symptoms

“Tension” not a treatable medical issue. Conversely, it was also believed by several participants that one's social and economic circumstances can cause physical illness, through “tension” or stress. Nonetheless, these participants still reported only somatic symptoms to health care providers. These examples illustrate how this group perceived the relationship between emotions and physical health:

“If a person is happy and laughs then only his/her body and mind will be healthy. If a person is not happy ... then automatically they will become like a patient.” – Relative of 54-year-old female, moderate-severe symptoms

“Once a man's heart starts getting anxiety he becomes weak in all aspects and starts getting fifty diseases ... When you have no money in your pocket, one after another illness will catch you. And if we get one disease it will lead to a thousand more diseases in your body.” – 64-year-old male, moderate symptoms

“All of our things got robbed ... Day and night I feel anxious and I worry for the same reason. And this anxiety and worry give rise to disease ... Then I get headaches. I can't see clearly from my eyes.” – 50-year-old female, moderate-severe symptoms

Despite believing that their physical health problems had psychosocial causes, all participants consulted health care providers primarily about somatic symptoms because these were considered to be medical problems that health workers are equipped to treat. Psychological and social problems were not reported during consultations because participants believed that health professionals have neither the time nor the capacity to address the wider context of their lives. For instance:

Interviewer: “Did you tell him about your thoughts and tension?”

Participant: “No, I shared nothing about this all ... The doctor will not give this much time to share about all the problems.” – 56-year-old female, moderate symptoms

“There is no treatment for sadness, dissatisfaction and tension. There is a treatment if you have some stomach pain or some other pain, but mind pain there is no treatment. It can't be possible, like if there is no production of wheat in my farm and I am in tension due to no production of wheat, can government give me wheat and take away my tension?” – 70-year-old male, moderate symptoms

Unless participants had somatic symptoms, therefore, participants were rarely seen to be truly ill and therefore in need of medical assistance. Thus, even those with high symptom scores were sometimes seen as insufficiently sick to warrant treatment. For example:

“We thought he will become fine on his own. Why take treatment, he is not having some severe disease” – Relative of 25-year-old male, moderate-severe symptoms

“I have a small problem ... I can manage it on my own ... I don't feel much difficulty because of it” – 35-year-old female, moderate-severe symptoms

Without exception, participants who talked of mental illness clearly distinguished this from “tension”. Unlike depression symptoms, mental illness was associated with psychotic symptoms and regarded as a legitimate medical issue. For instance:

“My mind is fine and well. I have only [a] tension problem ... In mental problems people behave strange from their mind, and tension is far different than that ... For mental people there are different doctors available which separately see only mental cases. Their medication and treatment all is different.” – 54-year-old woman, moderate-to-severe symptoms

“I don't have anything like I am crazy or some mental person ... I am not suffering from some ... attack of craziness ... I don't have that illness. I have tension related to my work. And isn't it quite normal to have tension related to work and household?” – 50-year-old woman, moderate-to-severe symptoms

Finally, a few interviewees explained “tension” as arising from individuals' thought patterns, rather than an inevitable response to one's circumstances. Those who expressed this view nonetheless rejected the possibility of treatment for depression symptoms because they believed that only the individual themselves can change their thoughts. For instance:

“I think only I myself can help me ... If I can make my mind not to think and do worry” – 60-year-old male, moderate symptoms

“Neither doctor understands tension nor is treatment available for tension ... Medication can't help, it will continue until one must decide to end it on [his] own ... Tension is actually a person's thinking ... It is not any physical illness” – relative of 54-year-old female, moderate-severe symptoms

Family members unaware of depression symptoms. Finally, while in some families interviewees stated that everyone takes their own decisions, in many there was a clear decision-maker; usually a male relative. In such families, the decision of whether to seek treatment depended on this person's perceptions of their relative's treatment needs. However, participants often declined to share their feelings with family members to avoid worrying them. For example:

"If I will explain the whole of my problem then obviously they all will get tension too ... What is the benefit in sharing with anyone ... They won't be able to solve my problems" – 33-year-old male, moderate symptoms

Many relatives could describe their family member's somatic complaints, but not their emotional state, suggesting that emotional experiences were not a common topic of conversation in many households. For instance, while these participants described issues relating to "tension", their relatives said:

"Only she can know about it ... I don't know what she thinks in her mind and what she doesn't think" – relative of 43-year-old female, moderate-severe symptoms

"She only has gum pain and nothing more. As per my knowledge she has nothing ... only gum pain" – relative of 36-year-old female, moderate symptoms

Structural and attitudinal barriers to health care. Structural and attitudinal barriers were also discussed, but applied to the use of health care in general, and were conditional on considering oneself to need health care. As described above, participants often perceived a need for treatment for somatic symptoms, but rarely considered treatment necessary or appropriate for depression symptoms specifically. Findings relating to structural and attitudinal barriers are briefly summarised in the supplementary material, as these may be applicable to service planning if demand for treatment were to increase. They also have relevance for understanding patterns of health service use for other reasons besides depression symptoms, which is outside the scope of the current study.

4. Discussion

4.1. Principal findings

This study identified the main barrier to seeking treatment for depression symptoms (operationalised as those in the PHQ-9 questionnaire) as lack of perceived need for treatment for these experiences. This is consistent with evidence from the World Mental Health Surveys, in which low perceived need for medical intervention was the primary barrier to treatment-seeking reported (Andrade et al., 2014; Thornicroft et al., 2017).

A primary reason for low perceived need was the conceptualisation of depression-like experiences as an understandable response to adversity, including both social and economic difficulties and physical health problems. Participants considered tension-related problems to be distinct from mental illness, and outside the purview of health services, as previously reported (Andrew et al., 2012; Cohen et al., 2018; Pereira et al., 2007). That the community largely view these experiences as a form of social suffering, rather than a health problem, is consistent with previous literature from India (Kermode et al., 2007; Paralikar et al., 2011; Patel and Prince, 2001; Rodrigues et al., 2003), although it is not necessarily specific to India (Ventevogel et al., 2013; Bromley et al., 2016; Cha et al., 2019).

In sum, the evidence presented here supports the notion that – in this context – the depression treatment gap largely reflects lack of demand for depression treatment, hence why increasing the supply of services had little impact. In this context, the reach paradigm offers an

incomplete framework with which to conceptualise the perceived needs of the community. By ignoring the interdependence between the mental, physical and social domains, this paradigm leads to a fundamental misalignment between the services offered and the priorities of those they are intended to serve. Below, we argue for a broader, more person-centred conceptualisation of mental health needs, drawing on the capabilities approach.

4.2. Implications

On separating the mental from the social. By ignoring the social contexts from which suffering arises, mental health services fail to address "what matters most" to many people (Kleinman, 2007). It was clear from participants' accounts that they did not merely seek to feel better; they wanted change in their circumstances. The capabilities approach offers an alternative framework for understanding people's needs that encapsulates what participants wanted: the freedom to lead lives they have reason to value, which requires increased agency over their own lives, and action on the systemic issues that limit people's capabilities (Venkatapuram, 2013).

Psychoeducation is often advocated to bridge the gap between professional and lay understandings of suffering (Jorm et al., 2006). However, participants' views are in line with the evidence on social determinants (Allen et al., 2014), and a growing evidence base supports their suspicion that treatment is less likely to be beneficial in the face of ongoing adversity (Cohen et al., 2009; Jakubovski and Bloch, 2014; Finegan et al., 2018). As noted by Marmot, there is little point in treating people and sending them back to the same conditions that made them sick (Marmot, 2015).

The movement towards "person-centricity" aligns with the capabilities approach, advocating a holistic understanding of people within their social context, and empowerment to allow people control over their own lives. This approach should push us to assess systematically what individuals and communities value, rather than attempting to change communities' priorities to align with services (Kirmayer and Ban, 2013). To fully understand their needs, we must recontextualise people's experiences and recognise that distress often reflects something that is going wrong in a person's "lifeworld" (Kirmayer et al., 2017).

In the current study, participants' needs included greater economic security, better working conditions, accountability and quality improvements in the public health system, reduced family conflict, and a route out of poverty for their children. Although primary care workers may have a role in identifying and referring individuals in need of such support, for instance through social prescribing models (South et al., 2008), primary care is unlikely to be the best platform to provide financial protection schemes or gender-based violence interventions, highlighting the limitations of the mhGAP-based model. Our findings support Knifton's plea to rediscover the public health principles of the Ottawa Charter, to empower individuals, families and communities while addressing the social determinants of health (Knifton, 2015). Investing in community-based social work is one strategy for addressing the proximal determinants of mental ill health and amplifying marginalised voices (Orr and Jain, 2015). The Atmiyata project in Maharashtra provides a model of how local "champions" can be trained to fulfil this role (Shields-Zeeman et al., 2017).

Using local idioms of distress can facilitate communication between health workers, service planners, and community members about the social, structural and economic determinants of distress (Lewis-Fernández and Kirmayer, 2019). The term "tension" is widely understood and non-stigmatising in this context (Weaver, 2017). The VISHRAM project in Vidarbha demonstrated that a community-based approach, using local idioms of distress, can lead to increased engagement with services compared to PRIME (Shidhaye et al., 2017a, 2017b).

On separating the mental from the biological. It must also be noted that the majority of people who screen for depression seek health care (Mathias et al., 2015; Soni et al., 2016), but the problems for which

help is sought are frequently somatic, not psychological. The World Health Organization's mhGAP guidelines include a module on medically unexplained symptoms (World Health Organization, 2016), which deserves greater attention to ensure that providers can recognise psychosomatic symptoms. However, it should not be assumed that all symptoms experienced by people who screen positive for depression are psychosomatic. Depression research in India often attributes somatic symptoms to psychological problems (Andrew et al., 2012; Cohen et al., 2018; Patel and Prince, 2001; Pereira et al., 2007), but rarely includes a clinical examination. It seems likely from the range of complaints reported here, exposure to shared risk factors, and the bidirectional links between mental and physical health (Prince et al., 2007), that many participants also experienced comorbid health problems. Participants' scepticism about the benefits of depression treatment without diagnosing and treating their physical complaints may well be warranted in the context of frequent comorbidities and weak standards of general health care.

Access to effective physical health care is an important modifiable social determinant of mental health (Allen et al., 2014). mhGAP guidelines recommend testing for and attending to comorbid conditions before commencing depression treatment (World Health Organization, 2016), but when primary care workers have around 2 min per consultation (Irving et al., 2017), this is extremely difficult to implement. India's health system faces many well-documented challenges, including lack of investment, poor management of public services, and low regulation of the private sector (Joumard & Kumar, 2015; Kumar et al., 2011). In rural Madhya Pradesh, 67% of health workers have no medical qualifications, and even qualified providers rarely give correct diagnoses or provide effective treatment (Das et al., 2012). Therefore, adults who screen positive for depression are unlikely to have their physical health needs met despite being in contact with health services. Standards of basic care matter for mental health not only because they undermine the community's faith in the system through which depression treatment is provided, but also because poor physical health causes mental ill health (Mendenhall et al., 2017; Singer et al., 2017). Substantial systems strengthening is required to achieve minimum standards of care. This should include investing in the workforce to ensure that health care providers have sufficient time, skills and motivation to fully assess patients' health needs, developing inter-sectoral linkages to refer people for social support, and incorporating a biopsychosocial orientation into the training of all health care professionals (Engel, 1978).

Finally, our results suggest that current treatment gap statistics should be treated with scepticism. In the World Mental Health Surveys, and PRIME, the treatment gap was measured in terms of self-defined treatment-seeking for mental or emotional problems (Rathod et al., 2016; Thornicroft et al., 2017). This assumes an important distinction between whether treatment is sought for emotional or somatic problems. However, many participants saw their health problems as inter-linked, possibly influenced by traditional systems of medicine that do not draw this dualist distinction (Fabrega, 2001), but only reported symptoms that fit with a biomedical viewpoint. We contend that dividing episodes of help-seeking into those that are mental health-specific or not is of questionable utility. As Pathare argues, the more important gap relates to the quality of support provided by both health and social care services to address the patients' inter-related mental health, physical health and social needs (Pathare et al., 2018). Again, the capabilities approach provides a framework that recognises the relevance of both access to high quality health care and action on social determinants in order to give people freedom to pursue the activities that they value.

Global mental health priorities. Closing the treatment gap for priority mental disorders, including depression, was the central goal of the field of global mental health until recently (Chisholm et al., 2007; Shidhaye et al., 2015a). The appropriateness of this goal must be considered in the knowledge that a large proportion of those who do not

currently receive treatment have no desire to do so. As many as 90% of those who meet criteria for depression have mild or moderate symptoms, who are unlikely to benefit from biomedical intervention (Patel, 2017). In a welcome recent move, the recent Lancet Commission on Global Mental Health and Sustainable Development recognised the need to broaden the agenda from the single-minded pursuit of closing the treatment gap to encompass action on the social determinants of mental ill health (Patel et al., 2018). The capabilities approach provides a useful framework from which to build on this agenda (White et al., 2016).

4.3. Strengths and limitations

Unlike previous studies of depression in India, this study used a community-based sample to explore the perspectives of those who do not seek treatment, and included relatives as well as screen-positive individuals, who may participate in health care decisions in this context.

Some limitations must be acknowledged. Data analysis was conducted in English, whereas the original interviews were conducted in Hindi. To avoid misunderstandings, the first author and second author (who is fluent in Hindi) consulted extensively during the analysis. As in any qualitative study, both researchers will have brought prior assumptions to the research based on their experience and educational backgrounds. We attempted to deliberately challenge these through ongoing discussion at each stage of the research process.

Participants' mental health status was determined using a screening tool, and other health conditions were not ruled out. Given the relatively low positive predictive value of this tool in Goa (Patel et al., 2008), it is therefore likely that the sample will have included some individuals who would not have received a depression diagnosis after a full clinical examination. However, all participants experienced depression symptoms as measured by the PHQ-9 and were therefore well-placed to comment on why they did not seek treatment for these, which was the aim of the study.

It is worth noting that mental health services in this area were recently established, and the awareness-raising activities conducted through PRIME were limited. It is therefore possible that with time, perceptions of the ability of health services to ameliorate psychological symptoms might have changed. However, high attrition rates from services and lack of impact of treatment on patients' functioning (Shidhaye et al., 2019) should caution us against assuming that word-of-mouth would necessarily encourage people to seek treatment.

We were also unable to recruit a family member for every person included, due to unavailability or participants declining to have a relative interviewed, so it was not possible to compare individual and family perspectives for every participant. However, based on the analysis of the fifteen relative interviews, we believe that we reached saturation of themes arising from relatives' accounts. Finally, we excluded participants who had sought treatment, which would have been a useful comparison group. The views of adults who are receiving depression treatment will be explored in a separate study, however, which can be compared with the current findings.

5. Conclusions

The depression treatment gap in rural India is largely attributable to low perceived need for treatment for depression symptoms. Many participants saw their psychological symptoms as inextricably linked with their social circumstances, and felt that biomedical interventions could not address these social issues. Participants also considered themselves to have multiple physical health needs, and during consultations prioritised somatic symptoms that are compatible with a biomedical model. To close the gap between the community's priorities and the services offered, interventions must be informed by the values and needs of the communities they serve. This is likely to require

linkages with community-based actors outside of the health sector, as well as systems strengthening to ensure that health services effectively respond to patients' inter-related biopsychosocial needs. The capabilities approach may provide a framework for conceptualising people's needs more holistically.

Declarations of interest

None.

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Author Contributions Section

Tessa N Roberts: Conceptualisation, Methodology, Investigation, Formal Analysis, Data Curation, Writing- Original draft preparation, Funding Acquisition, Ritu Shrivastava: Investigation, Project administration, Data Curation, Validation, Mirja Koschorke: Conceptualisation, Methodology, Vikram Patel: Supervision, Writing- Reviewing and Editing, Rahul Shidhaye: Supervision, Resources, Writing- Reviewing and Editing, Sujit D Rathod: Conceptualisation, Supervision, Writing- Reviewing and Editing.

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Appendix A. Supplementary data

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